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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[30Day-15-15CT]

Agency Forms Undergoing Paperwork Reduction Act Review

The Centers for Disease Control and Prevention (CDC) has submitted the following information collection request to the Office of Management and Budget (OMB) for review and approval in accordance with the Paperwork Reduction Act of 1995. The notice for the proposed information collection is published to obtain comments from the public and affected agencies.

Written comments and suggestions from the public and affected agencies concerning the proposed collection of information are encouraged. Your comments should address any of the following: (a) Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility; (b) Evaluate the accuracy of the agencies estimate of the burden of the proposed collection of information, including the validity of the methodology and

assumptions used; (c) Enhance the quality, utility, and clarity of the information to be collected; (d) Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submission of responses; and (e) Assess information collection costs.

To request additional information on the proposed project or to obtain a copy of the information collection plan and instruments, call (404) 639-7570 or send an email to omb@cdc.gov. Written comments and/or suggestions regarding the items contained in this notice should be directed to the Attention: CDC Desk Officer, Office of Management and Budget, Washington, DC 20503 or by fax to (202) 395-5806. Written comments should be received within 30 days of this notice.

Proposed Project

Sudden Death in the Young Registry - New - National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

Sudden Death in the Young (SDY)

Every year, infants, children and adolescents die suddenly and unexpectedly from previously undiagnosed conditions. Sudden Death in the Young (SDY) is defined as any death of an infant, child, or young adult (up to the age mandated by each state), investigated by the medical examiner or coroner office, except homicides, suicides, overdoses, poisonings, or other external injury deaths, for example from fire or as a passenger in a motor vehicle accident.

SDY deaths are not routinely or systematically reported, so estimates of the annual incidence of SDY vary broadly due to differences in definitions, inconsistencies in classifying cause of death on death certificates, variable ages and types of study populations, and differing case ascertainment methodologies. Because complete information has not been collected on the incidences, causes, and risk factors, lack of evidence fuels disagreements about the best prevention approaches.

SDY Registry

To address this knowledge gap, the Centers for Disease Control and Prevention (CDC), in collaboration with the National Heart, Lung, and Blood Institute (NHLBI) and the National

Institute of Neurological Disorders and Stroke (NINDS) at the National Institutes of Health (NIH) have implemented the Sudden Death in the Young (SDY) Registry (DP14-1403) to provide technical assistance to improve the current work of existing Child Death Review (CDR) programs. The SDY Registry is an expansion of the CDC's Sudden Unexpected Infant Death (SUID) Case Registry (currently DP12-1202), which provides technical assistance to state grantees so they can monitor sudden unexpected deaths in children up to age one in their state.

By building on CDC's successful SUID Case Registry, the SDY Registry also provides technical assistance to grantees so they can improve their state's information on infant and child deaths. This includes two additions to their usual CDR program: 1) entering new SDY information from sources already available at CDR reviews, 2) conducting an advanced clinical review of a sub-set of SDY cases to allow for a more technical and medical review of information already compiled. The intended result will be complete and timely grantee-based infant and child death information that can be used to guide program and policy decisions at the state and local levels.

Child Death Review (CDR)

Child Death Review (CDR) programs function in every state, and the program is often mandated by the state. Case reviews occur at the local and state level, depending on the state. States use their data to inform prevention strategies and to evaluate the success of state programs in reducing infant and child deaths as well as producing annual reports.

The National Center for the Review and Prevention of Child Death (NCRPCD) provides support and technical assistance to CDR programs. This program is funded by the Health Resources and Services Administration (HRSA). The NCRPCD support covers a broad array of process-oriented CDR issues such as forming multi-disciplinary teams, moving from state to local reviews and strengthening partnerships with the local forensic community. In addition, the NCRPCD provides support to CDR programs who voluntarily participate in the web-based NCRPCD Case Reporting System. This Case Reporting System provides a standardized way to compile infant and child death information, already accessed and reviewed by state and local teams. Local and state teams own their data and identifiable data (if entered at all) is not available to anyone but the state that owns the data. The NCRPCD Case Report (Version 4.0), available to all CDR programs that use the Case Reporting System, will include new SDY variables. The CDC is asking SDY Registry grantees to enter new

SDY variables into this pre-existing system and to use an advanced review to provide a more in-depth review of a sub-set of cases.

Information Collection Request (ICR)

The activities relevant to this Information Collection Request (ICR) are that SDY Registry (i.e., grantee) CDR programs will convene an advanced clinical review team of physicians with specialties relevant to SDY, and will, through the advanced clinical review and its usual CDR process, enter new SDY variables specific to SDY deaths. The data will be entered into the NCRPCD Case Reporting System, version 4.0. The SDY variables are available to all users of the Case Reporting System, grantees and non-grantees alike. In addition, unfunded local and state CDR teams may wish to conduct specialized advanced clinical reviews and are not prohibited from doing so. The SDY Registry aims to improve data completeness and timeliness of the data entered by providing technical assistance to grantees only.

For the purposes of this ICR, a "respondent" is a SDY Registry grantee funded by CDC. As a grantee for CDC's cooperative agreement, the respondent agrees to compile a specifically defined set of SDY information about a defined set

of deaths of children through the state's CDR program. CDC estimates that 900 cases will be reported over a three-year period. There are no costs to respondents other than their time. The total annualized burden hours are 2,250.

Estimated Annualized Burden Hours

Type of respondent	Form Name	No. of Respondents	No. Responses per Respondent	Average Burden per Response (in hours)
State health personnel	SDY Module	9	300	30/60
Pediatric cardiologists	SDY Module	9	300	5/60
Epileptologists	SDY Module	9	300	5/60
Neurologists	SDY Module	9	300	5/60
Forensic pathologists	SDY Module	9	300	5/60

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